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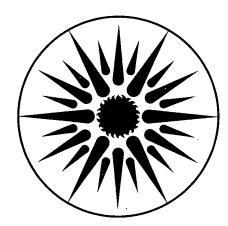
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ENERGY & ENVIRONMENT DIVISION

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B.L. Wallin, A.R. Houser, D.W. Merrill, and S. Selvin

January 1994



ENERGY & ENVIRONMENT DIVISION

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Data Available from Birth and Death Registries and Cancer Registries in the United States

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January 1994

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Introduction

In the United States, cancer registries have been compiling data for decades, and state vital statistics offices have been compiling birth and death data for nearly a century. Although this information has been well used for disease surveillance and various studies, it could be better exploited by making it more readily available, reducing the duplication of effort that occurs when researchers at the private, city, county, state, and federal levels work separately on their data collection and disease investigations. This report summarizes the nationwide availability of birth and death records and cancer registry data, with particular emphasis on subcounty geographic detail, such as zip code and census tract.

Birth and death data are available at the county level for the entire United States from the National Center for Health Statistics. However, county level data are inadequate for small area studies of potential environmental hazards. Hazards of current interest to the Department of Energy (DOE) include DOE facilities, nuclear power plants, and sources of electromagnetic radiation such as broadcasting towers and power lines.

For additional information about existing health data bases, see Gable CB,¹ Flynt *et al.*,² and Frisch *et al.*³

Methods

The information compiled in this report was obtained between June and August, 1990, by telephoning vital statistics offices and cancer registries in the United States. Special effort was made to ascertain the geographic detail and coverage of the data, with emphasis on census tract codes and zip codes. Where zip code and/or census tract data were collected, we obtained additional information regarding the completeness of the coverage and the years covered by the data. In each case, we attempted to determine the person to contact when requesting the data, and any

special protocols required to obtain the data. In December, 1993, follow-up letters were sent to each registry and vital statistics office to verify the correctness of the data.

In Tables 1 and 2, "Data Available" refers to the earliest year for which birth and death records were collected by the state. "Data On Line" refers to the earliest year for which computer-readable birth or death records are available. "Zip Code Available" refers to the earliest year for which zip code information is available for the birth or death records. "Census Tract Available" refers to the earliest year for which census tract information is available and for which counties if not statewide.

In Table 3, "Start Date" refers to the earliest year for which cancer records were collected by the registry. "Pop'n Based?" indicates whether the registry is population-based or when it became population-based (a registry is considered population-based if it collects cancer cases among all residents within the region covered by that registry). "Zip Code" and "Census Tract Available" serve the same purpose as in the birth and death tables.

Appendices A, B, and C contain additional information for birth and death registries, cancer registries, and cancer registry services, respectively. "Comments" includes any additional information that pertains to data from that state. "Ordering" indicates any special procedures for obtaining data.

Results

All states have birth and death data on line except for Montana (Tables 1 and 2); three-quarters of the states have computer-readable data from 1970 forward. Zip codes are available for birth records in 44 of the 51 states, and are available for death records in 39 states (in this report, District of Columbia is considered a state). Census tracts are available for birth and death records in 22 and 20 states, respectively, but only the District of Columbia, Hawaii, Rhode Island, and Washington cover the entire geographic area.

Table 3 indicates the availability of cancer registry data in the United States. Forty-six of the 51 states have cancer registries, and 41 of the registries (excluding Alaska) are population-based, but only 24 have data before 1980. In some states, regional population-based registries existed before state-wide reporting was in place; these are noted under "Comments" in Appendix B. In other cases, population-based reporting was instituted after the establishment of the registry. Alaska is population-based, but the population covered is only Native Americans, Eskimos, and Aleuts. Forty-three of the cancer registries collect zip code data, but only 21 collect census tract data. Only eight states have cancer registries that collect census tract data for the entire state.

Appendices A and B indicate the person to contact when requesting data from that state. They also contain miscellaneous information that may be useful when ordering data.

Appendix C summarizes the cancer data services in the United States. Some of these services are shared by several states and may be helpful when planning a study involving more than one state.

Discussion

The data in the aforementioned databases can be used for case-control or cohort studies, provided that strict confidentiality requirements are met by the investigator. They are also useful for ecologic studies, where zip codes or census tracts can link birth, death, or cancer incidence data with census population data and databases of environmental exposures. For example, Jablon *et al.* performed an ecologic study of cancer in populations living near nuclear facilities.⁴ In other studies, ecologic data have been used to examine the relationship between birth defects and pesticide use by county⁵ and by zip code.⁶

Ecologic studies have well-known limitations. Special techniques are required

for analyzing ecologic summary data, in order to avoid introducing bias related to the "ecologic fallacy". When linking an environmental exposure with the geographic distribution of a disease, it must be remembered that exposure is an average value pertaining to a geographic area and may not be generalizable to individuals within the population. Misclassification of exposure may result, reducing the likelihood of finding a significant association between exposure and disease. Other sources of misclassification bias exist; for example, zip codes for rural areas are not reliable because many people use post office boxes that may be up to 40 miles from home.

For disease codes most vital statistics offices and cancer registries use *International Classification of Diseases* (ICD)⁸ or *International Classification of Diseases for Oncology* (ICD-O)⁹ codes. To keep pace with advances in medical knowledge, ICD and ICD-O definitions are revised approximately every ten years by international agreement. As a result, time trends of disease rates may have unavoidable discontinuities in those years when code changes occurred.

Census tract boundaries, zip code boundaries, and, to a lesser extent, county boundaries may change over time, making it more difficult to define the population at risk when using data that span a longer time period. It is important to determine that the recorded deaths and the estimated population at risk correspond to exactly the same geographic area and time period.

Racial classification is another variable that is not constant over time. The classification for whites presents a major problem: due to increasing ethnic awareness, many Hispanic Americans who identified themselves as "white" in the 1970 Census preferred to call themselves "other race" in the 1980 and 1990 Censuses. The bias affects primarily census denominators and not, for example, mortality or cancer incidence numerators. The result is an upward bias, beginning around 1980, of white disease rates in areas with large Hispanic populations. The upward bias exceeds 10 percent in some areas. Race-corrected population

estimates, and not original census data, should be used as population denominators. (Race-corrected county population estimates may be purchased from Demo-Detail Inc., Richard Irwin, Director; 2303 Apple Hill Rd. Alexandria, VA 22308. (703) 780-9563.)

Migration may cause spurious associations or mask real associations. Deaths are classified by location of residence at time of death, which may be ambiguous for people who have more than one residence and especially for diseases like cancer which may have long latency periods. Annual totals generally serve as numerators when calculating disease rates. In contrast, the population denominators collected by the Bureau of the Census refer to the physical location of the person on Census Day, for example April 1, 1990. In a location with seasonal population variation, for example, Nantucket County, Massachusetts, a systematic bias exists because the census population measurement is not an accurate estimate of the average annual population.¹¹ It may be useful to understand the reciprocal case notification agreements that exist between various states and between various registries in order to recognize the impact that migration has on data from that state.

Of particular concern are effects due to the migration of military personnel. When studying an area that contains a military base, the epidemiologist must ascertain how military personnel are counted by the cancer registry, by the vital statistics office, and by the Bureau of the Census. A large military population within an area could alter the estimate of the number exposed and susceptible to disease.

It must be kept in mind that birth and death records are only a crude measure of health effects. Hexter *et al.* have determined that the reporting of birth defects on the birth certificate is poor.¹² Furthermore, the cause of death reported on the death certificate may fail to represent the actual underlying cause of death. This discrepancy may arise when the death certificate is completed by the physician on duty at the time of death, and not by the patient's regular physician. For a more complete

understanding of the disease-risk association, especially for chronic diseases, it is essential to consult the multiple cause of death section on the death certificate.

Assumptions and conclusions regarding cancer incidence data are dependent on whether or not the registry is population-based. If the registry is not populationbased, the registry population will not be representative of the area which it serves.

Although many states do not have statewide registries, useful cancer data may be obtained from individual hospital registries within that state. A list of approved hospital cancer registries is published by the Commission on Cancer of the American College of Surgeons.¹³

Despite the limitations associated with ecologic analysis of routinely collected surveillance data, the insight provided by such studies is valuable. Often less expensive than other methods, ecologic studies may suggest etiologic hypotheses, and they can aid in planning more thorough investigations of the association between a suspected environmental health risk and disease.

<u>Acknowledgments</u>

We wish to thank Carl Quong and Robert Goldsmith for programmatic support of epidemiologic data activities in the Department of Energy. We are grateful to Harvard Holmes for project resources and personal involvement that were essential to the completion of this report.

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¹ Gable CB. A Compendium of Public Health Data Sources. Am J Epidemiology 1990; 131(3): 381-394.

² Flynt JW, Norris CK, Zaro S, Kitchen SB, Kotler M, Ziegler A. State Surveillance of Birth Defects and Other Adverse Reproductive Outcomes. U.S. Department of Health and Human Services 1987.

³ Frisch JD, Shaw GM, Harris JA. Epidemiologic Research Using Existing Databases of Environmental Measures. Archives of Environmental Health 1990; 45(5): 303-307.

Table 1: Birth Data Availability

State	Data	Data	Zip Code	Census Tract
	Available	On Line	<u>Available</u>	<u>Available</u>
Alabama	1908	1960	1988	Not available
Alaska	1913	1974	1968	Not available
Arizona	1900	1950	1968	1960-Maricopa, Pima
Arkansas	1913	1985	1985	Not available
California	1905	1960	1982	Not available
Colorado	1900	1975	1975	1975-Adams, Arapahoe,
				Douglas, Denver; 1978-
	e.			Boulder, Jefferson, Pueblo;
				1987-Gilpin, Clear Creek
Connecticut	1897	1959	1988	1981-urban areas (85-95% c
				state)
Delaware ·	1920	1968	1986	1986-New Castle County
District of Columbia	1890	1968	1980	1968-entire district
Florida	1917	1970	1970	1975-Broward; 1991-
				Hillsborough
Georgia	1919	1983-92	1985	Fulton County locally entered
-lawaii	1853	1985	N/A	1968-entire state
daho	1911	1954	1989	Not available
llinois	1916	1916	1989	Chicago only
ndiana	1907	1970	1979	Not available
owa	1880	1965	1989	Not available
Kansas	1911	1911	1978	Not available
Kentucky	1911	1976	1976	Not available
_ouisiana	1912	1915	1983	Not available
Maine	1892	1976	1984	Not available
Maryland	1903	1970	1986	1983-urban areas
Massachusetts	1841	1969	1986	1972-Boston city; 1986-urba
				areas (85% of state)
Michigan	1867	1969	1978	1970-88: Kent, Grand Rapid
				city, Detroit city; 1989-prese
				not available

Table 1: Birth Data Availability

State	Data	Data	Zip Code	Census Tract
	Available	On Line	<u>Available</u>	Available
Minnesota	1900	1959	1989	1970-Minneapolis & St. Paul
Mississippi	1912	1958	1979	Not available
Missouri	1911	1968	1972	1968-St. Louis city; 1975-St.
		•		Louis county
Montana	1907	N/A	N/A	Not available
Nebraska	1905	1958	N/A	1970-Dakota &Washington (to
				1988), Sarpy (to 1990), Douglas
				& Lancaster (to present)
Nevada	1911	1968	1991	Not available
New Hampshire	1940	1971	1987	Not available
New Jersey	1878	1967	1989	Not available
New Mexico	_. 1919	1964	1980	Not available
New York*	1900	1960	1978	1969-Albany, Broome, Erie,
•				Monroe, Nassau, Niagara,
				Onandaga, Saratoga, West-
				chester; 1975-Suffolk; 1982-
				Oneida; 1985-Rensselaer,
	•			Schenectady; 1987-Rockland
New York City*	1900	1968	1983	New York city only
North Carolina	1914	1956	1988	Not available
North Dakota	1893	1978	1978	Not available
Ohio	1908	1959	N/A	1979-urban areas
Oklahoma	1908	1975	1975	Not available
Oregon	1903	1970	1984	1978-Multnomah, Portland city
Pennsylvania	1906	1960	1979	Not available
Rhode Island	1893	1968	N/A	1972-entire state
South Carolina	1915	1970	1989	1970-Florence, Richland,
				Greenville, Charleston
South Dakota	1905	1960	1980	Not available
			•	

Note: New York state and New York City birth data are available from separate agencies.

Table 1: Birth Data Availability

State	Data Available	Data On Line	Zip Code Available	Census Tract Available
Tennessee	1917	1960	1989	1976-Hamilton, Knox, Shelby
Texas	1903	1964	1977	Not available
Utah	1905	1970	1978	Not available
Vermont	1850	1979	N/A	Not available
Virginia	1913	1975	1975	Not available
Washington	1907	1968	1989	1980-entire state
West Virginia	1917	1968	1979	Not available
Wisconsin	1907	1959	1979	Not available
Wyoming	1909	1978	N/A	Not available

Table 2: Death Data Availability

State	Data	Data	Zip Code	Census Tract
	Available	On Line	<u>Available</u>	Available
Alabama	1908	1960	1988	Not available
Alaska	1913	1977	1968	Not available
Arizona	1900	1992	1968	1960-Maricopa, Pima
Arkansas	1913	1980	1985	Not available
California	1905	1960	1989	Not available
Colorado	1900	1975	1975	1975-Adams, Arapahoe,
				Douglas, Denver; 1978-
				Boulder, Jefferson, Pueblo;
				1987-Gilpin, Clear Creek
Connecticut	1897	1949	1989	1981-urban areas (85-95% of
				state)
Delaware	1930	1968	1986	1986-New Castle County
District of Columbia	1890	1968	1980	1968-entire district
Florida	1917	1970	1991	1975-Broward
Georgia	1919	1983-92	N/A	Not available
Hawaii	1853	1991	N/A	1968-entire state
Idaho	1911	1954	1989	Not available
Illinois	1916	1916	1965	Not available
Indiana	1900	1970	1979	Not available
lowa	1880	1954	N/A	Not available
Kansas	1911	1989	1978	Not available
Kentucky	1911	1976	1987	Not available
Louisiana	1912	1944	1978	Not available
Maine	1892	1970	N/A	Not available
Maryland	1903	1970	1986	1983-urban areas
Massachusetts	1841	1969	1987	1972-Boston city; 1987-urban
				areas (85% of state)
Michigan	1867	1968	1989	1970-Kent, Grand Rapids city,
				Detroit city

Table 2: Death Data Availability

State	Data	Data	Zip Code	Census Tract
	Available	On Line	Available	Available
Minnesota	1900	1944	1992	1970- Minneapolis & St. Paul
Mississippi	1912	1958	N/A	Not available
Missouri	1911	1968	1972	1975-St. Louis city and county
Montana	1907	N/A	N/A	Not available
Nebraska	1905	1958	N/A	1970-Dakota &Washington (to
				1988), Sarpy (to 1990), Douglas
				& Lancaster (to present)
Nevada	1911	1968	1991	Not available
New Hampshire	1940	1968	N/A	Not available
New Jersey	1878	1967	1989	Not available
New Mexico	1919	1962	1989	Not available
New York*	1900	1960	1978	1969-Albany, Broome, Erie,
				Monroe, Nassau, Niagara.
				Onandaga, Saratoga, West-
				chester; 1975-Suffolk; 1982-
				Oneida; 1985-Rensselaer,
				Schenectady; 1987-Rockland
New York City*	1900	1968	1983	1983-New York City only
North Carolina	1914	1956	1988	Not available
North Dakota	1893	1978	1978	Not available
Ohio	1908	1959	N/A	1979-urban areas
Oklahoma	1908	1975	1975	Not available
Oregon	1903	1970	1986	1978-Multnomah, Portland city
Pennsylvania	1906	1960	1979	Not available
Rhode Island	1943	1968	N/A	1972-entire state
South Carolina	1915	1970	1989	1970-Florence, Richland,
				Greeneville, Charleston
South Dakota	1905	1960	1988	Not available
Tennessee	1917	1949	1989	1976-Hamilton, Knox, Shelby

Note: New York state and New York City death data are available from separate agencies.

Table 2: Death Data Availability

State	Data	Data	Zip Code	Census Tract
	<u>Available</u>	On Line	<u>Available</u>	<u>Available</u>
Texas	1903	1964	1989	Not available
Utah	1905	1956	1978	Not available
Vermont	1850	1968	N/A	Not available
Virginia	1913	1975	1975	Not available
Washington	1907	1968	1988	1980-entire state
West Virginia	1917	1948	1979	Not available
Wisconsin	1907	1958	1989	Not available
Wyoming	1909	1978	N/A	Not available

Table 3: Cancer Data Availability

	State	Agency	Start Date	Pop'n Based?	Zip Code	Census Tract Available
	Alabama Alaska Arizona	Alabama Dept. of Health Alaska Area Native Health Service Arizona Cancer Registry	N/A 1969 1980	N/A Yes 1992	N/A N/A 1980	N/A Not available Available for childhood & testicular cancer cases diagnosed 1965 to 1989 in Maricopa & Pima counties
	Arkansas California	Central Arkansas Radiation Therapy Institute California Cancer Surveillance Section	1982 1973	No Yes	N/A 1973	Not available 1973-San Francisco Bay Area & Los Angeles; 1984-Orange County; 1988- statewide
	Colorado	Colorado Central Cancer Registry	1968	1988	1968	1979-Adams, Arapahoe, Boulder, Denver, Jefferson, Douglas, & Gilpin, counties
	Connecticut	Connecticut Tumor Registry	1935	Yes	1935	1973-83: partially available; 1984-88: entire state (80% complete)
17	Delaware District of Columbia Florida	Delaware State Tumor Registry Central Cancer Registry Cancer Epidemiology, HSDE	1972 1950 1979	Yes Yes 1981	1972 1950 1979	1980-entire state Available for entire district 1981-available for 85% of state;
	Georgia	Georgia Center for Cancer Statistics	1969	No	1975	unavailable for rural routes & P.O. boxes 1975-Fulton, Dekalb, Clayton, Gwinnett, & Cobb counties
	Hawaii Idaho Illinois Indiana Iowa	Hawaii Tumor Registry Cancer Data Registry of Idaho Illinois Cancer Registry State Cancer Registry State Health Registry of Iowa	1960 1969 1985 1987 1973	1960 Yes Yes 1987 Yes	1960 1969 1985 1987 1973	1979-entire state Not available 1985-entire state except for rural routes Not available 1978-Dubuque, Woodbury, Black Hawk, Linn, Scott, Polk, Pottawattamie, & parts of Warren and Dallas counties
	Kansas Kentucky Louisiana	Cancer Data Service Kentucky Cancer Registry Louisiana Tumor Registry	1969 1986 1974	1983 1991 1974	1970 1986 1974	Not available Not available 1974-Orleans, Jefferson, & St. Bernard parishes; 1984-southern state; 1988- entire state
	Maine	Maine Cancer Registry	1983	Yes	1983	Not available

Table 3: Cancer Data Availability

State	Agency	Start Date	Pop'n Based?	Zip Code	Census Tract Available
Maryland	Maryland Cancer Registry	1982	Yes	1982	1982-Anne Arundel, Baltimore, Carroll, Calvert, Charles, Hartford, Howard, Montgomery, Prince Georges counties & Baltimore city; 1990-entire state
Massachusetts	Massachusetts Cancer Registry	1982	Yes	1982	1982-entire state
Michigan	Michigan Cancer Surveillance System	1985	Yes	1985	Not available now but may be in the future
- Minnesota	Minnesota Cancer Surveillance System	1988	Yes	1988	Not available now but will be in the future
Mississippi	State Department of Health	N/A	N/A	N/A	N/A
Missouri	Bureau of Smoking, Tobacco, & Cancer	1984	Yes	1984	Not available
Montana	Montana Central Tumor Registry	1979	Yes	1979	Not available
Nebraska	Nebraska Cancer Registry	1987	Yes	1987	Not available
Nevada	Statewide Cancer Registry Program	1979	Yes	1979	Not available
New Hampshire	New Hampshire State Cancer Registry	1986	1987	1986	Not available
New Jersey	New Jersey State Cancer Registry	1979	Yes	1979	1979-more complete for northern (urban) areas and less complete for rural areas; about 75% of file is tracted
New Mexico	New Mexico Tumor Registry	1967	1969	1967	1973-Bernalillo county; 1991-Santa Fe county
New York	New York Cancer Registry	1940	1976	1976	1976-entire state; derived from MCD codes
North Carolina	North Carolina Central Cancer Registry	1987	1990	1987	Not available
North Dakota	State Department of Health	N/A	N/A	N/A	N/A
Ohio	Cancer Data System, Inc.	1975	1987	1975	1975-Cuyahoga County
Oklahoma	Oklahoma Cancer Registry	1990	No	1990	Not available
Oregon	Oregon Health Division	N/A	N/A	N/A	N/A
Pennsylvania	State Health Data Center	1982	1985	1982	Not available
Rhode Island	Rhode Island Cancer Registry	1986	Yes	1986	1986-entire state
South Carolina	S.C. Department of Health	1990	No	N/A	Not available
South Dakota	South Dakota Department of Health	N/A	N/A	N/A	N/A
Tennessee	Tennessee Cancer Reporting System	1986	Yes	1986	Not available
Texas	Cancer Registry Division	1949	1976	1949	Not available

Table 3: Cancer Data Availability

State	Agency	Start Date	Pop'n Based?	Zip Code	Census Tract Code
Utah	Utah Cancer Registry	1966	1966	1966	1973-Utah, Salt Lake, Davis, & Weber counties; 1978-Toole County
Vermont	Vermont Cancer Registry	1993	1993	1993	Not available
Virginia	Virginia Tumor Registry	1970	1990	1970	Not available
Washington	Cancer Surveillance System	1991	Yes	1974	1974-King, Pierce, Snohomish, Thurston, Whatcom, & Kitsap counties
West Virginia	Office of Epidemiology	1991	Yes	1991	Not available.
Wisconsin	Wisconsin Cancer Reporting System	1976	1978	1976	Not available
Wyoming	Wyoming Central Tumor Registry	1962	1962	1962	Not available

Appendix A: Birth & Death Data Ordering Information

Alabama

Dorothy Harshbarger, State Registrar Center for Health Statistics Alabama State Health Department P.O. Box 5625 Montgomery AL 36103-5625 (205) 613-5426

<u>Alaska</u>

Al Zangri, Chief Bureau of Vital Statistics Alaska Department of Health P.O. Box H Juneau AK 99811-0675 (907) 465-3992

Arizona

Mary Symcox Office of Vital Records Arizona State Department of Health P.O. Box 3887 Phoenix AZ 85030 (602) 542-1084

Arkansas

Werner Haney, Director of Vital Statistics Center for Health Statistics, Slot 19 Arkansas Department of Health 4815 West Markham Little Rock AR 72205-3867 (501) 661-2510

California

Charles Chan Vital Statistics Section Department of Health Services 714 P Street, Room 1494 Sacramento CA 95814 (916) 657-3057 Fax: (916) 324-5599

Comments:

Alabama application for Release of Vital Records and signed confidentiality statement must be submitted and approved before records with individual identifiers are released.

Ordering:

Comments:

Send request with research summary & protocol.

Ordering:

If approved, cost is \$70/hr for on-line data pulls. Off-line priced separately depending on request scope.

Comments:

Approval by Dept's Subject Review Committee required. Signed confidentiality statement required. No follow-back permitted. Identifiers on records must not be used or contacted.

Ordering:

Non-certified copies \$2 each. When submitting protocol, include how you maintain confidentiality of records & what final disposition will be.

Comments:

Ordering:

Comments:

Ordering:

Cost: \$175 for first year, \$50 for each additional year.

Colorado

Carol Garrett, Section Chief Office of Vital Statistics Colorado Department of Health

4300 Cherry Creek Drive South HSUR - HS - A5

Denver CO 80222-1530 (303) 692-2160 Fax: (303) 782-0095

Connecticut

Kathryn E. Friedrich Registrar of Vital Records Department of Public Health & Addiction Services 150 Washington Street Hartford CT 06106 (203) 566-6545

Delaware

Mary E. Cannon Health Planning and Resources Management Department of Health and Social Services P.O. Box 637 Dover DE 19903 (302) 736-4776

District of Columbia

Carl W. Wilson, Chief Research and Statistics Division D.C. Department of Human Resources 613 G Street, 9th Floor Washington DC 20001 (202) 727-0682 Fax: (202) 727-3396

Florida

Kenneth T. Jones, Acting Chief Office of Vital Statistics P.O. Box 210 Jacksonville FL 32231-0042 (904) 359-6929

<u>Georgia</u>

Michael R. Lavoie, Director Vital Records Service Department of Human Resources Room 217 H Atlanta GA 30334 (404) 656-4750 Comments:

Ordering:

Comments:

Birth & death data requests for research must be reviewed & approved by agency's Human Investigations Committee.

Ordering:

Call for copy of HIC protocol.

Comments:

All data requests must be reviewed and may require Board of Health approval. Confidentiality assurances are required.

Ordering:

Comments:

Ordering:

Comments:

Requests involving confidential information require study protocol and Data Purchase and Use Agreement to be submitted for review by the State.

Ordering:

Special programming requests are on a fee-forservices basis.

Comments:

Hold-harmless agreement required. If contact with subjects is necessary, IRB or DHR Human Subjects Committee approval needed.

Ordering:

Send a written summary with the protocol.

<u>Hawaii</u>

Dr. Alvin Onaka, State Registrar Office of Health Status Monitoring Hawaii Department of Health P.O. Box 3378 Honolulu HI 96801 (808) 548-6454

Idaho

Janet M. Wick, Head Statistician Bureau of Vital Statistics Cooperative Center for Health Statistics Statehouse Boise ID 83720 (208) 334-5978

Illinois

Larry Davis
Division of Vital Records
State Department of Public Health
605 West Jefferson St.
Springfield IL 62702-5097
(217) 782-6553

<u>Indiana</u>

James M. Miklos, Administrative Officer Planning & Information Services Indiana State Departmentof Health 1330 West Michigan Street PO Box 1964 Indianapolis IN 46206-1964 (317) 633-8515

<u>lowa</u>

Larry Coghlan lowa Department of Health Lucas State Office Building Des Moines IA 50319 (515) 281-3583

Kansas

Dr. Lorne Phillips, State Registrar Center for Health & Environmental Statistics Kansas Health Department Landon State Offiice Building 900 SW Jackson St. Topeka KS 66612 (913) 296-8075

Comments:

Dept requests a gratis copy of any report using Hawaii data.

Orderina:

Request copy of confidentiality form before ordering. Birth data requests must be reviewed by Data Committee.

Comments:

Data available on tape from 1954. Limited disclosure of confidential information.

Ordering:

Research application required.

Comments:

Ordering:

Comments:

Before 1979, zip code data are incomplete.

Ordering:

Cost: approximately \$600/ yr. Send study protocol with request.

Comments:

Birth data are available between 1959-61 & since 1965.

Ordering:

Research agreement required. Fee for copy or search is \$10.00.

Comments:

Zip code reporting for deaths is optional & was optional for births prior to 1989.

Ordering:

Fee must be paid prior to processing of request.

Kentucky

Mrs. Jo Warren Health Data Branch

Division of Vital Records & Health Development

275 East Main Street, CHR Building

Frankfort KY 40621 (502) 564-2757

Louisiana

Mr. William Barlow, State Registrar Office of Vital Statistics Louisiana Department of Health P.O. Box 60630 New Orleans LA 70160

(504) 568-8353

Maine

Ellen Naor, State Registrar Office of Data, Research, and Vital Statistics 35 Anthony Avenue Statehouse Station #11 Augusta ME 04333-0011

(207) 624-5445

Maryland

Ms. Julia Davidson-Randall, State Registrar Department of Health and Mental Hygiene General Services Administration 201 West Preston Street, Room 519 Baltimore MD 21201 (410) 225-5830

(410) 225-5830 Fax: (410) 333-5958

Massachusetts

Elaine Trudeau, State Registrar Registry of Vital Records & Statistics 150 Tremont Street, Room B-3 Boston MA 02111 (617) 727-0036

Fax: (617) 727-8108

Michigan

George Van Amburg Office of the State Registrar Michigan Department of Public Health P.O. Box 30195 Lansing MI 48909 (517) 335-8675 Comments:

Ordering:

Comments:

Death records are transferred to the Louisiana State Archives after 50 years. Research regulations control disclosure of birth & death data which include identifiers.

Ordering:

Comments:

Ordering:

Comments:

Ordering:

Comments:

Ordering:

Approval required for birth data & suggested for death data.

Comments:

Ordering:

Researchers must submit study protocol to receive research fee rate.

A - 4

Minnesota

John Oswald

Office of Health Statistics State Department of Health 717 Delaware Street SE

Minneapolis MN 55440

(612) 623-5187 Fax: (612) 623-5043

<u>Mississippi</u>

Nita Cox Gunter

Bureau of Information Resources Mississippi State Department of Health P.O. Box 1700

Jackson MS 39215-1700

(601) 960-7977

Missouri

Wayne Schramm, Chief Bureau of Health Data Analysis Missouri Department of Health

P.O. Box 570

Jefferson City MO 65102

(314) 751-6278 Fax: (314) 526-4102

Montana

Sam Sperry, Chief Vital Statistics Bureau

Montana Department of Health

PO Box 200901 Helena MT 59620 (406) 444-4228

Nebraska

Mark Miller

Division of Health Data Systems Nebraska State Health Department 301 Centennial Mall South P.O. Box 95007

Lincoln NE 68509-5007 (402) 471-0355

Nevada

Mary Howard Office of Vital Statistics Nevada State Department of Health 505 East King Street Carson City NV 89710

(702) 687-4480

Comments:

Ordering:

There is a charge for computerized files.

Comments:

Research & epidemiology studies require NDI

approval.

Ordering:

Comments:

Ordering:

Comments:

Ordering:

Comments:

Ordering:

Must detail the data fields requested and the purpose of acquiring data and how or in what form they will be published. If request meets proper purpose laws, a legal agreement must be signed.

Comments:

New Hampshire

Mr. Frank Novak, Acting State Registrar Bureau of Vital Records and Health Statistics Health & Human Services Building 6 Hazen Drive Concord NH 03301-6527

(603) 271-4651 Fax: (603) 271-3447

New Jersey

Charles Karkut, State Registrar Bureau of Vital Statistics C.N. 370 Trenton NJ 08625 (609) 292-8085 Fax: (609) 392-4929

New Mexico

Betty Hileman, Chief Bureau of Vital Statistics New Mexico Health & Environment Dept. 1190 St. Frances Drive Santa Fe NM 87503 (505) 827-2342

New York (excl New York City)

Gene Therriault, Director Bureau of Biometrics New York Department of Health Empire State Plaza Concourse Room C-144 Albany NY 12337-0044 (518) 474-3189

(518) 474-3189 Fax: (518) 486-1630

New York City

Dr. Stephen Stellman, Asst Commissioner Biostatistics & Epidemiological Research New York City Department of Health 125 Worth Street New York City NY 10013 (212) 566-6371

North Carolina

Kathryn McLawhorn Center for Health & Environmental Statistics P.O. Box 27687 Cotton Building Raleigh NC 27611-7687 (919) 733-4728 Comments:

Ordering:

Comments:

Ordering:

Comments:

Severe confidentiality & follow-back restrictions. NDI required for death data. Other uses by proposal approval only.

Ordering:

Lengthy process.

Comments:

For New York city, see separate record.

Ordering:

Confidentiality statement is required.

Comments:

For NY state outside of NY city, see separate record.

Ordering:

Comments:

Data prior to 1968 are not readily available.

North Dakota

David Mayer

Division of Vital Statistics

North Dakota Dept Health & Consolidated Labs

State Capitol Building

Judicial Wing, 600 East Blvd.

Bismarck ND 58505-0200

(701) 224-2314

Fax: (701) 224-4727

Ohio

Mary F. Smith, Statistical Analysis Unit

Ohio Department of Health

Health Policy Data Center

P.O. Box 118

Columbus OH 43266-0118

(614) 644-7808

<u>Oklahoma</u>

Roger Pirrong, State Registrar

Bureau of Vital Statistics

Vital Records Division

Department of Health

P.O. Box 53551

Oklahoma City OK 73152

(405) 271-4040

Oregon

Edward Johnson II, State Registrar

Center for Health Statistics

P.O. Box 14050

Portland OR 97214-0050

(503) 731-4109

Pennsylvania

Patricia W. Potrzebowski, Director

Division of Health Statistics and Research

State Health Data Center

Pennsylvania Department of Health

Harrisburg PA 17108 (717) 783-2548

Rhode Island

Roberta Chevoya

Division of Vital Records

101 Cannon Building

3 Capitol Hill

Providence RI 02908

(401) 277-2812

Comments:

Ordering:

Comments:

Orderina:

Specify request in detail to obtain cost & time

estimate.

Comments:

Ordering:

Cost estimate requires detailed written request.

Comments:

Ordering:

Cost: \$300 per data year.

Comments:

Minor civil division codes available since 1961.

Ordering:

Comments:

Ordering:

Cannot create public use tapes. Confidentiality agreement required. Fee for specially tailored

reports.

South Carolina

Betsv Barton

Office of Vital Records & Public Health Statistics South Carolina Dept. of Health & Env. Control

2600 Bull Street Columbia SC 29201 (803) 734-4681 Fax: (803) 734-5131

Comments:

Restricted by law/regulation.

Ordering:

Send written requests with specification as to the data items needed.

South Dakota

Dorris Donner, State Registrar

Vital Records

Department of Health 445 East Capitol

Pierre SD 57501-3185

(605) 773-4961

Comments:

Ordering:

Specify data items needed. Confidentiality required.

Tennessee

Jean Moss, Director

Health Statistics & Information Division of Information Resources

Department of Health 419 Cordell Hull Building Nashville TN 37247-0360

(615) 741-1954 Fax: (615) 532-1886 Comments:

Ordering:

Texas

Mr. Tom Pollard, Director

Bureau of Vital Statistics Texas Department of Health

1100 West 49th Austin TX 78756

(512) 458-7362

Comments:

Birth data on line 1926-28, and since 1941. Birth data confidential until age 50; death data confidential for 25 years after death.

Orderina:

Send fee and request for confidential information to

Committee Request for Personal Data.

City and town codes are available.

Utah

John E. Brockert, State Registrar

Bureau of Vital Records Utah Department of Health

P.O. Box 16700

Salt Lake City UT 84116-0700

(801) 538-6186

Comments:

Zip code not verified.

Ordering:

Send written requests with specification as to the data items needed and the years of data required.

Vermont

Charles Bennett, Ph.D.

Division of Public Health Analysis & Policy Vermont Department of Public Health

P.O. Box 70

Burlington VT 05402

(802) 863-7300 Fax: (802) 863-7425 Ordering:

Comments:

Virginia

Ron Hyman

Center for Health Statistics Virginia Department of Health 109 Governor Street, Room 307

Richmond VA 23219 (804) 786-6206 Fax: (804) 371-4800

Washington

Craig Parker, Research Analyst Center for Health Statistics, MS-ET-14

Department of Health 1112 Quince SE Olympia WA 98504-7814

(206) 586-6008 Fax: (206) 753-4135

West Virginia

Chuck Bailey, Jr., State Registrar Vital Statistics Office West Virginia Department of Health Building 3, Capitol Complex Charleston WV 25305 (304) 558-0155

(304) 558-0155 Fax: (304) 558-1051

Wisconsin

Clare Schneider Center for Health Statistics P.O. Box 309 Madison WI 53701 (608) 267-7808 Fax: (608) 267-0352

Wyoming

Cindy McCaffrey
Vital Records
Wyoming Department of Health
Hathaway Building
Cheyenne WY 82002
(307) 777-7591

Comments:

Ordering:

Comments:

Ordering:

Comments:

Ordering:

Research agreement required. Variable costs. Death tape \$100 plus \$10 for each year included.

Comments:

Orderina:

Fee for data on tape is approximately 2.5 cents/record, plus computer costs.

Comments:

Appendix B: Cancer Registry Data Ordering Information

<u>Alabama</u>

Charles H. Woernle, MD **Bureau of Disease Control** Alabama Department of Public Health 434 Monroe Street #900 Montgomery AL 31630-3017 (205) 613-5325 Fax: (205) 288-5021

Alaska

Dr. Anne Lanier Office of Community Health Services Alaska Area Native Health Service 250 Gambell Street Anchorage AK 99501 (907) 271-4011

Arizona

Georgia Armenta Yee, Manager Arizona Cancer Registry Department of Health Services 1400 W. Washington St Phoenix AZ 85007 (602) 542-7320 Fax (602) 542-1753

Arkansas

Dr. Deborah O. Erwin Central Arkansas Radiation Therapy Institute (CARTI) P.O. Box 5210 Little Rock AR 72215 (501) 644-8573

California

John L. Young, Jr., Dr.P.H., Chief California Cancer Surveillance System Department of Health Services PO Box 942732 Sacramento CA 94234-7320 (916) 327-4663:

Fax: (916) 327-4657

Colorado

Mrs. Robin Bott, Director Colorado Central Cancer Registry State Department of Health 4300 Cherry Creek Drive South Denver CO 80222 (303) 692-2542 Fax: (303) 782-0095

Comments:

Registry data exist on microfilm only for 1960's and 1970's. There are currently 22 hospital registries in the state.

Ordering:

Comments:

State does not have a registry; cancer cases collected for Native Americans (Indians, Eskimos, Aleuts) only since 1969.

Ordering:

Comments:

Estimated completeness for 1990 is 76%. Mandatory reporting began 1992. Uses Rocky Mountain Cancer Data System.

Ordering:

Comments:

Estimated 75% completeness. There are 13 hospital registries in the state.

Ordering:

Comments:

San Francisco area has been part of SEER since 1973. Statewide reporting since 1988. Has reciprocal reporting agreement with Nevada.

Ordering

Comments:

Denver area population-based since 1979. Statewide reporting since 1988.

Connecticut

Mr. John T. Flannery, Director Connecticut Tumor Registry Dept. of Public Health & Addiction Services 150 Washington Street Hartford CT 06106 (203) 566-3975

Delaware

Carol Marker, Program Administrator Delaware State Tumor Registry 3000 Newport Gap Pike Wilmington DE 19808 (302) 995-8606 Fax: (302) 995-8689

District of Columbia

Director Cancer Control Bureau 425 I Street, N.W., Room 2001 Washington DC 20001 (202) 576-8888

Florida

Mr. Douglas G. Palin Cancer Epidemiology, HSDE Dept. of Health & Rehabilitative Services State Health Office, 1317 Winewood Boulevard Tallahassee FL 32399-0700 (904) 488-2907 Fax: (904) 922-9299

Georgia

Dr. Jonathon M. Liff, Deputy Director Georgia Center for Cancer Statistics Dept. of Epidemiology & Biostatistics Emory University School of Public Health 1462 Clifton Road, N.E. Atlanta GA 30329 (404) 727-8713 Fax: (404) 727-8737

Hawaii

Dr. Marc Goodman Hawaii Tumor Registry 1236 Lauhala Street, Suite 402 Honolulu HI 96813 (808) 586-9750 Fax: (808) 587-0024

Idaho

Stacey Peterson, ART, CTR, Director Cancer Data Registry of Idaho 802 West Bannock, Suite 500 Boise ID 83702-5842 (208) 338-5100 Fax: (208) 338-7800

Comments:

Joined SEER Program in 1973. ZIP code not available on computer before 1992, but available on paper abstracts.

Ordering:

Comments:

Uses Rocky Mountain Cancer Data System.

Orderina:

Comments:

Ordering:

Comments:

Ordering:

Comments:

Metropolitan Atlanta has been part of SEER since 1975, rural environs since 1978. Voluntary reporting since 70's is about 50% complete. Data since 1980 are on line.

Ordering:

Comments:

Joined SEER Program in 1973.

Ordering:

Comments:

Includes Idaho residents treated out-of-state & non-residents treated in Idaho. Uses Rocky Mountain Cancer Data System.

Illinois

Holly L. Howe, Ph.D., Chief Division of Epidemiologic Studies Illinois Department of Public Health 605 West Jefferson Street Springfield IL 62761 (217) 785-1873 Fax: (217) 524-1770

<u>Indiana</u>

Martha Graves, RRA, CTR State Cancer Registry Indiana State Board of Health P.O. Box 1964 1330 West Michigan Street Indianapolis IN 46206-1964 (317) 633-8424 Fax: (317) 633-0847

<u>lowa</u>

Mrs. Kathleen McKeen, Admin. Dir. State Health Registry of Iowa 100 Westlawn Bldg. S. Iowa City IA 52242 (319) 335-8609 Fax: (319) 335-8610

Kansas

Dr. Frederick F. Holmes, Director Cancer Data Service University of Kansas Medical Center College of Health Science 3901 Rainbow Boulevard Kansas City KS 66160-7312 (913) 588-4725 Fax: (913) 588-4701

Kentucky

Mr. Thomas C. Tucker Kentucky Cancer Registry Lucille Parker Marky Cancer Center 800 Rose St. Lexington KY 40536-0093 (606) 257-4582 Fax: (606) 258-1902

<u>Louisiana</u>

Dr. Vivien W. Chen Louisiana Tumor Registry Louisiana Department of Health Room 305, P.O. Box 60630 New Orleans LA 70160-0630 (504) 568-2616 Fax: (504) 568-8650

Comments:

Ordering:

Requests must be submitted in writing. Confidential data requests must follow ISCR guidelines.

Comments:

Some data exist before 1987, but are incomplete.

Ordering:

Comments:

Joined SEER Program in 1973. Some cancer data collected 1969-71.

Ordering:

Comments:

Zip code data not reliable in rural areas because of the use of PO boxes.

Ordering:

Comments:

Ordering:

Comments:

Orleans, Jefferson, & St. Bernard parish data available since 1974, southern state since 1983, statewide data since 1988.

Maine

Ms. E. Melanie Lanctot Maine Cancer Registry 157 Capitol St. State House, Station #11 Augusta ME 04333 (207) 287-5187 Fax: (207) 287-4172

Comments:

Ordering:

If identifiers are needed, contact registry for copy of protocol.

Maryland

Dorothy Damron Maryland Cancer Registry University of Maryland at Baltimore Dept. of Epidemiology & Preventive Medicine 660 W. Redwood St., 324 Howard Hall Baltimore MD 21201 (410) 706-6447 Fax: (410) 706-8013

Comments:

Ordering:

Massachusetts

Susan Gershman, Director Massachusetts Cancer Registry Department of Public Health 150 Tremont Street, 5th Floor Boston MA 02111-1126 (617) 727-9291

Comments:

Ordering:

Michigan

George Van Amburg Michigan Cancer Surveillance System P.O. Box 30195, 3500 North Logan Lansing MI 48909 (517) 335-8677

Comments:

Ordering:

Dependent upon the nature of the data request, may require submission of a protocol & an application for review by an independent scientific advisory panel.

<u>Minnesota</u>

Sally Bushhouse, DVM, MPH Minnesota Cancer Surveillance System Minnesota Department of Health 717 Delaware SE Minneapolis MN 55440 (612) 623-5216 Fax: (612) 623-5743

Comments:

Ordering:

Call to discuss the request prior to sending anything written.

Mississippi

Cindy Widdig Cancer Consultant State Department of Health PO Box 1700 2423 N. State Street Jackson MS 39205 (601) 960-7854

Comments:

There are 11 hospital registries in the state.

Missouri

Dr. Jian C. Chang, PhD.
Bureau of Smoking, Tobacco, & Cancer
Missouri Department of Health
201 Business Loop 70 West
Columbia MO 65203
(314) 876-3224
Fax: (314) 443-3592

Comments:

Ordering:

Montana

Debbi Hellhake Montana Central Tumor Registry Dept. of Health & Environmental Sciences Cogswell Building C118 Helena MT 59620 (406) 444-2618 Fax: (406) 444-1803 Comments:

Ordering:

Send copy of the study protocol with request for data.

Nebraska

Monica Seeland, RRA, Health Data Manager Nebraska Cancer Registry Department of Health Omaha NE 68509-5007 (402) 390-0352 Comments:

Regulations for release of information for research purposes are in effect.

Ordering:

Nevada

Phyllis Wiggins, Director Nevada Statewide Cancer Registry Program 620 Belrose St. Las Vegas NV 89158 (702) 486-5065 Comments:

Uses Rocky Mountain Cancer Data System. Has reciprocal notification agreement with California.

Ordering:

New Hampshire

Dr. Marguerite Stevens New Hampshire Cancer Registry PO Box 186 Hanover NH 03775-3802 (603) 650-1106 Fax: (603) 650-1493

Comments:

Ordering:

New Jersey

Debra M. Harlan, Director Epidemiology & Research Services Cancer Registry Program New Jersey Department of Health 3635 Quaker Bridge Road, CN 369 Trenton NJ 08625-0369 (609) 588-3500 Fax: (609) 588-7431 Comments:

Four-county SEER data available 1984-88; statewide data since 1979.

Ordering:

To obtain data, call Betsy Kohler, then send request.

New Mexico

Dr. Charles R. Key, Med. Director New Mexico Tumor Registry 900 Camino de Salud, N.E. Albuquerque NM 87131 (505) 277-5541 Fax: (505) 277-8572

Comments:

Joined SEER Program in 1973. Also collects data on Native American residents of Arizona.

Ordering:

Data requests should be sent to Dr. Ben Hankey, SEER Program, NCI, 9000 Rockville Pike, Bethesda MD 20892-4200; (301) 496-8510.

New York

Mark S. Baptiste, Ph.D. New York Cancer Registry Department of Health, Office of Public Health Corning Tower, Room 536, Empire State Plaza Albany NY 12237-0683 (518) 474-2255 Fax: (518) 474-2086

Comments:

Ordering:

North Carolina

Dr. Tim Aldrich or Dale Herman North Carolina Central Cancer Registry Center for Health & Environmental Statistics Dept of Environment, Health & Natural Resources P.O. Box 29538 Raleigh NC 27626-0538 (919) 715-4555

Comments:

Strong research involvement with CCR. Good capability for geographic studies.

North Dakota

Barbara Burgum Lee, Coordinator Cancer Prevention & Control Program ND State Dept. of Health & Consolidated Labs Division of Health Promotion & Education 600 E. Boulevard Avenue Bismarck ND 58505-0200 (701) 224-2333

Orderina:

Submit request in writing. A review protocol is followed. Please call with questions.

Ohio

Felicia Cammarata, Vice President Cancer Data System, Inc. 1226 Huron Road Cleveland OH 44115 (216) 696-6900 Fax: (216) 781-4905

Comments:

Ordering:

Oklahoma

Dr. Fred Walker, Administrator Oklahoma Cancer Registry - 0200 Oklahoma State Department of Health 1000 NE 10th Street Oklahoma City OK 73117-1299 (405) 271-7353

Comments:

Population-based for Cuyahoga County beginning in 1987. Covers Cuyahoga County, Lake Geauga County, parts of Medina County, Toledo, & Massilon.

Ordering:

Comments:

Oregon

Donald Austin, MD Oregon Health Division 800 NE Oregon St., Suite 730 Portland OR 97232 (503) 731-4025

Pennsylvania

Patricia W. Potrzebowski, Ph.D. State Health Data Center Commonwealth of Pennsylvania Department of Health P.O. Box 90, Room 127 Harrisburg PA 17108-9990 (717) 783-2548

Rhode Island

Dr. John P. Fulton, Administrator Rhode Island Cancer Registry Rhode Island Department of Health 3 Capitol Hill Providence RI 02908-5097 (401) 277-2553 Fax: (401) 277-1272

South Carolina

Margaret Senn Dept. of Chronic Diseases South Carolina Dept. of Health 2600 Bull Street Columbia SC 29201 (803) 734-4790

South Dakota

Everett Putnam, Statistician South Dakota Department of Health Pierre SD 57501-3182 (605) 773-3365

Tennessee

Mr. George Wade Tennessee Cancer Reporting System Department of Health and Environment 419 Cordell Hull Building Nashville TN 37247-0360 (615) 741-0685 Fax: (615) 532-1886

Texas

Barry Wilson, Public Health Technician Cancer Registry Division Texas Department of Health 1100 West 49th Street Austin TX 78756 (800) 252-8059 Fax: (512)-502-0862 Comments:

No central registry yet, but plans are underway to establish one soon. Largest hospital registry is Kaiser system, covering 20% of metropolitan area.

Ordering:

Comments:

Collects minor civil division codes (borough & township).

Ordering:

Comments:

The Hospital Association of Rhode Island collects the cancer data & uses the Rocky Mountain Cancer Data System.

Ordering:

The name of the principal investigator is required.

Comments:

Twelve hospital registries cover 60% of the cases. Pilot registry began in 1990 & includes Charleston, Dorchester, & Berkeley counties.

Ordering:

Comments:

Orderina:

Comments:

Ordering:

Data requests may need to be approved by the advisory committee.

Comments:

Data are complete for 5 regions for 1976-1985. Mortality data available for entire state through 1991.

<u>Utah</u>

William P. McWhorter, MD, MPH, Director Utah Cancer Registry Research Park 420 Chipeta Way, Suite 190 Salt Lake City UT 84108 (801) 581-8407 Fax: ((801) 581-4560

Comments:

Part of the SEER Program.

Ordering:

Vermont

Leslie A. Weber, MS, Director Vermont Cancer Registry Division of Epidemiology & Disease Prevention Department of Health P.O. Box 70 Burlington VT 05402 (802) 865-7749 Fax: (802) 863-7425

Comments:

Surveyed hospital registries in 1990. Statewide registry began in November, 1993. Uses CANSUR/NET software.

Ordering:

<u>Virginia</u>

M. Gillian Thompson, CTR, Director Virginia Cancer Registry State Health Department, Room 114 PO Box 2448 Richmond VA 23218 (804) 786-1668 Fax: (804) 786-1076

Comments:

Prior to 1989, reporting was voluntary; 85% complete.

Ordering:

Washington

Joseph Castorina, MD, MPH
Department of Health
Health Promotion and Disease Prevention
PO Box 47835
Olympia WA 98504
(206) 586-7625
Fax: (206) 586-5440

Comments:

Seattle area joined SEER Program in 1974; statewide reporting began in July, 1991. Ordering:

West Virginia

Loretta E. Haddy, MA, MS, State Epidemiologist Surveillance and Disease Control West Virginia Bureau of Public Health 1422 Washington Street, East Charleston WV 25301 (304) 558-5358 Fax: (304) 558-6335

Comments:

Statewide collection of breast and cervical cancer cases only before 1992; all sites reportable beginning in 1993.

Ordering:

Send letter of request explaining funding and purpose of the study.

Wisconsin

Ms. Jerri Linn Phillips, MA, CTR
Wisconsin Cancer Reporting System
Department of Health & Social Services
1 W. Wilson Street, Room 172, P.O. Box 309
Madison WI 53701-0309
(608) 266-0633
Fax: (608) 267-0352

Comments:

Cancer has been reportable since 1933, but registry did not begin until 1976.

Ordering:

Send letter with request, explaining who is funding the study and what is the purpose of the study. Strict confidentiality requirements. Wyoming Mary I. Seaver Wyoming Central Tumor Registry
Division of Health and Medical Sciences Hathaway Building, 4th floor Cheyenne WY 82002 (307) 777-7958 Fax: (307) 777-5402

Comments:

Ordering: Send letter with request explaining purpose of study.

Uses the Rocky Mountain Cancer Data System.

Appendix C: Cancer Data Services

ACTUR

Major J.A. Halvorson Medical Policy Liaison Officer Defense Medical Systems Support Center 5109 Leesburg Pike, Suite 917 Falls Church VA 22041-3201 (703) 756-0904

Fax: (703) 756-0971

Cansur NET

Mary Crist, CTR

Cansur NET

American College of Surgeons
55 East Erie Street

Chicago IL 60611

(312) 649-3920

Fax: (310) 649-4600

C/Net

Dr. Barry Gordon, Director C/Net Project California Public Health Foundation 2001 Addison St, Suite 210 Berkeley CA 94704 (510) 540-0778

ELM Services/PREMIER Cancer Registry System

Dr. Lee Mortenson ELM Services/PREMIER Cancer Registry System 11600 Nebel St., Suite 201 Rockville MD 20852 (301) 984-1242 Fax: (301) 770-1949

Medical Registry Services

William Weiss, President Medical Registry Services One University Plaza Hackensack NJ 07601 (201) 487-2266 Fax: (201 487-5184

PC Dash

Anna Marie Davidson PC Dash New Mexico Tumor Registry 900 Camino de Salud, N.E. Albuquerque NM 87131-5306 (505) 277-5541 Fax: (505) 277-8572

Comments:

Registry of military cases since 1989. They are retrospectively collecting data for cases since 1979.

Comments:

Provides cancer data management software for facilities throughout the United States. Assists in data submission to state, central, and national organizations.

Comments:

Provides cancer registry software for hospital registries throughout the United States. Does not collect or store data, but assists central registry data collection.

Comments:

Provides data system services for hospitals which enter data on PC's. The data are uploaded to the ELM mainframe system. ELM's on-line, interactive aggregate National Oncology Data Base contains clinical & demographic information on over 800,000 cases & can be queried using Sybase or SPSS.

Comments:

Provides cancer registry software & support for over 200 hospital registries nationwide.

Comments:

Data collection system for State of New Mexico & Arizona Native Americans. Also the system is used by the Native American Health Service registry in Alaska. Reporting package includes summary and survival reports, plus cross-tabulations.

Rocky Mountain Cancer Data System Larry Derrick Rocky Mountain Cancer Data System 420 Chipeta Way, Suite 120 Salt Lake City UT 84108 (801) 581-4307 Fax (801) 581-5704

TUMORS
Gail Jolitz
The Upper Midwest Oncology Reg. System (TUMORS)
6500 Excelsior Blvd, PO Box 650
Minneapolis MN 55440
(612) 932-5140
Fax (612) 932-5512

Comments:

Provides services for the Walla Walla WA, Spokane WA, Cleveland OH, DC, AZ, CO, DE, ID, MT, NV, RI, UT, & WY registries.

Comments:

Provides a support system to 23 hospital registries in MN, ND, & SD. Hospital registries collect & store the data; a copy of data is maintained in aggregate database at TUMORS.

LAWRENCE BERKELEY LABORATORY UNIVERSITY OF CALIFORNIA TECHNICAL INFORMATION DEPARTMENT BERKELEY, CALIFORNIA 94720